

Appendix 2

Focus Group Discussion Guide and Session Notes

Please note before
printing: this document is
38 pages long.

SIM Focus Group Discussion Guide

8-21-13

Confidential – not to be shared in advance with group participants

Care Plan experience

1. **Have you ever, or do you currently have a care plan?** If so, how was your plan developed? What was your role in developing it? Did anyone help you develop it? Do you feel you were the one who called the shots in developing your plan or do you feel like someone else made most of the decisions?
2. **How do you feel about your current plan?** What works well? What doesn't work well?
3. **Does/did your plan have an annual budget?** Was that budget fair? Was it enough to cover the services you wanted? Have you ever had any funds left over? If so, what happened to those funds? Have you ever over-spent your budget?

Developing your plan

4. If you don't have a care plan or have never had one, **what would you picture that developing your plan would involve? What would you like to see in your plan?**
5. What kind of **support would you want or need in not only creating, but implementing your Health Spending Plan?** Would you rather have someone take the lead in developing your plan? or make your own decisions through options counseling?
6. **What incentives would you like available in your plan to help improve your health or help you lead a healthier life?**

Service choices

7. **Is there anything in your current plan, or services that you receive, that you are not willing to give up?**
8. **What services would you like to have available to you that you don't have now?** What services that you receive now would you like to see more of?
9. **What would you use the flexibility in your Health Services Plan for?**
10. **Are there any obstacles you face in the current system that you don't like and that should be eliminated in this potential new one?**

Budget

- 11. What (how much) do you think a fair, annual long-term care health spending plan budget would be for you?**
- 12. What do you think should happen if you need to overspend your annual budget? What do you think should happen if you underspend your annual budget?**
- 13. What would you use any surplus of money for?**

Evaluation

- 14. How do you want to participate in the evaluation of this new long-term-care service model?** How do you want to participate in the evaluation of the insurance company who works with you? How about the individual or organization that helps you develop your plan?

Education

- 15. What tools would you like to be made available to you to provide you with information about any new Medicaid long-term-care health insurance program?**
- 16. What would you like to know about the health care providers you “shop” for?** How would you like this information to be made available to you? (How do you get this type of information now?)

Hopes

- 17. If you were in charge of any change in the way New Hampshire’s long term care service delivery system works what would *you* do?** Would it look anything like the model we are proposing? What makes sense? What doesn’t?

Additional questions used in last 3 focus groups on final model design

What information would you want to know about someone who provides services to you?

What help would you want in managing your own budget?

What scares you about managing your own budget?

What do you or would you find helpful in managing your own budget?

What would influence you in selecting a team coordinator? What would you want to know? What would you want the coordinator to do?

If you are already “in the system” what would be the best way to help you transition to the new one?

Focus Group

Target population: Older Adults

Organization: Service Link, Atkinson NH

August 23, 2013

Conducted by Louis Karno & Company Communications

of participants: 5

Questions

1. What would you like to know about the health care providers you “shop” for?

How would you like this information to be made available to you? (How do you get this type of information now?)

- How can we get the information we need?
- Will I have a case manager? If so, how much involvement will they have in making my plan?
- Will they help me make decisions?
- Will they help me save money?

2. What do you think should happen if you underspend your annual budget?

- It should roll over and you should be told up front that will happen
- There shouldn't be much left over if the plan was developed with the person's needs wants and values in mind
- Money in next year's budget to be used for any unforeseen things

3. What would you use any surplus of money for?

- Skype
- Transportation
- In home services- nurse

4. What would you use the flexibility in your Health Services Plan for?

- Unforeseen things
- Savings
- Physical Therapy

5. What kind of support would you want or need in not only creating, but implementing your Health Spending Plan? Would you rather have someone take the lead in developing your plan? or make your own decisions through options counseling?

- Direction from the team leader is important
- A Team leader to tell you what is important
- Someone to oversee the bill

6. If you don't have a care plan or have never had one, what would you picture that developing your plan would involve? What would you like to see in your plan?

- Engagement in community
- Wellness program/reward/incentive
- Consumer directed choice/ Independent decisions
- A couple different options

7. What would incent you to save if you could?

- Making it clear in the beginning where the extra money goes
- Educate the consumer on how they can dispute bills, save etc.

8. If you were in charge of the Medicaid system in NH would a revamp of the services you've used look anything like this model?

- Make Medicaid more simple to get into it
- Educate people about exactly what they need to know
- Will the Team Leader be online or an actual person
- If you can't fund the team leader position the rest of the flow chart won't work

9. What should happen with any left over money in your budget?

- Rollover

Focus Group

Target population: Counseling Staff

Organization: Service Link, Atkinson NH

August 23, 2013

Conducted by Louis Karno & Company Communications

Attendees: 5

Questions:

- 1. What tools should be made available to staff and seniors to provide information?**
 - A “go to person” for information/trainee
 - Training refreshers
 - More navigable website for Health and human service and service link
 - More resources
 - Better technology
- 2. Are there any obstacles you see that seniors or their families face in the current long-term care system that should be eliminated in this potential new one?**
 - Over income under resourced person has need but doesn't meet the medical eligibility,
 - Person is waiting for something to happened to land them in a nursing home
- 3. How non-traditional will the array of service be?**
 - Mowing the lawn
 - Transportation
 - Food pantry/soup kitchen assistance
 - Emergency living
- 4. In your experience, from the client perspective, how much guidance do people want? Does it vary based on certain characteristics or situations? And if so, what are those? What percentage of the people you work with fall into those categories?**
 - 30% want help, 70% don't want help
 - We are trained to present options, not to be biased.
 - 80% would want control 20% would want it done for them
 - Let them do the leg work from that motivation their case manager
 - Managed care is sometimes more a bang for the buck than an agency with several options

5. **From your experience and perspective, what challenges will consumers face in developing a health care plan that meets their, or their loved-one's needs?** How will they react to the opportunity to do this? How should this be presented or described to them?
 - People are too sick by the time they are in this model to be able to afford healthier eating etc.
6. **Are there any obstacles you face in the current system that you don't like and that should be eliminated in this potential new one?**
 - Timeliness-process time, potential 6 months before services start,
 - Direction/education - knowing their options (pre model),
7. **If you were in charge of any change in the way New Hampshire's long term care service delivery system works what would you do?** Would it look anything like the model we are proposing? What makes sense? What doesn't?
 - Flushing out roles of team leader, case load, broad array of services
 - How do we reach out to the people who may be eligible but don't know?
 - Give consumer more access to knowledge
 - Reach out to people who aren't literate
 - Clarification of the role of team leader
 - Reinvestment plan

Focus Group

Target Population: People with developmental disabilities

Family Support Council, Atkinson NH

August 28, 2013

Conducted by Louis Karno & Company Communications

of participants: 12

Questions:

- 1. If you don't have a care plan or have never had one, what would you picture that developing your plan would involve? What would you like to see in your plan?**
 - More control over personal care taker
- 2. Is there anything in your current plan, or services that you receive, that you are not willing to give up?**
 - Case manager periodically checking up with son
 - Multi year relationship with the doctor my child works well with
 - Access to residential programs
- 3. What would you use the flexibility in your Health Services Plan for?**
 - Residential programs
 - More control over personal care taker
 - Dermatologists
- 4. Are there any obstacles you face in the current system that you don't like and that should be eliminated in this potential new one?**
 - Not many places in NH are taking Medicaid anymore or not taking new patients
 - Waitlists
 - Area agencies haven't done a good job at cost containment
 - Need more choices
 - There aren't enough people with knowledge of what the individual needs
- 5. What would you use any surplus of money for?**
 - Dental care
 - Dermatologist
 - Equipment to make the house wheelchair accessible
- 6. How do you want to participate in the evaluation of this new long-term-care service model? How do you want to participate in the evaluation of the insurance company who works with you? How**

about the individual or organization that helps you develop your plan?

- See the bill
- Have someone go over the bill

7. What would you like to know about the health care providers you “shop” for? How would you like this information to be made available to you? (How do you get this type of information now?)

- What hospitals and what providers will be in the new plan?
- Will out of state providers be included in this plan?
- How do private insurance fall into the Medicaid

8. If you were in charge of any change in the way New Hampshire’s long-term care service delivery system works what would you do? Would it look anything like the model we are proposing? What makes sense? What doesn’t?

- Flexibility in keeping the doctors
- Flexibility in keeping continuity of service
- 1 case manager not multiple ones, where you are just a number

9. If you don’t have a care plan or have never had one, what would you picture that developing your plan would involve? What would you like to see in your plan?

- Reasonable justification

10. What (how much) do you think a fair, annual long-term care health spending plan budget would be for you?

- Based on individual’s needs

11. What do you see this model being called?

- Social model
- Life model
- Individual Service Plan

Concerns and Questions for DHHS:

- The model looks too medical
- Will the “team leader” be able to follow “son” and do the check up that is currently working?
- “Don’t screw up what is already working”
- Will the system be preserved as it is now?
- Will there be a waiver if you don’t want any of the options? Opt out?
- The new design looks like a lot like “ in house court waiver “ –
- Who is doing the hiring? Who is doing the training and scheduling?

- Want guarantee on if the current waivers will stay in place
- What about the current weight list? How does that fit into the current system
- Importance of the workforce getting the money they need
- Care takers “ make my life”, what will happen to mine?
- Is this model an effort to make the ceo’s more money?

Focus Group

Target Population: People with physical disabilities

Community Campus, Portsmouth, NH

August 28, 2013

Conducted by Louis Karno & Company Communications

of participants: 7

Questions:

1. Do you currently have a care plan? What is your experience?

- 2 separate plans through 2 separate agencies
- 1 case managers for each agency
- Experience has been needs only no wants and values
- Agencies don't have knowledge about other agencies
- Agencies don't want to educate consumers about other agencies

2. What do you think of 1 rather than 2 separate plans?

- Having it all under one umbrella would be great
- Consulted 75% for personal needs
- Having one case manager rather than multiple

3. What types of services would you want to be covered by your plan that isn't currently covered?

- Acupuncture
- Funding ending too soon
- Alternative/treatment therapy/ non traditional providers
- Nutritionist
- Personal choice of providers
- Mental health coverage outside the community health centers especially people that have coverage under Medicare and Medicaid, counselors, if they take Medicaid not Medicare you can't see them if you have dual eligibility

6. If you could save money for additional services what could you see that money going towards?

- More choice in providers
- Less of alternative and more integrated services
- Dental services

7. What do you envision in your plan? Things that should be included in your plan?

- Personal care services
- Transportation service
- Modified vehicle financial assistance / maintenance/ car payments
- Service Dog expenses

- Wheelchair assistance/ Wheelchair vendors information
- Provider qualifications
- Non-traditional provider option
- PCP (personal care service providers) options need to be evaluated and modified based on the individual
- Physical Therapy that covers more than acute diagnosis
- A lot of practitioners won't take mental disability patients who have dual eligibility
- Muscle relaxation medication
- Alternative therapy/medicine
- Nutritionist
- Ipad
- Internet connection/ monthly payments
- Reduced costs for Internet connection

8. Is there anything in your care plan that isn't working for you?

- Poor use of resources by the case manager
- Face to face interviews
- Needing a wheel chair update more frequently
- Acupuncture being covered, funding ending too soon

9. As far as budget what would you like to see change?

- More flexibility in budget
- Use first years budget as a guideline for the next year

10. What incentives would you like available in your plan to help improve your health or help you lead a healthier life?

- Eating healthier/food stamp
- Use PCA hours to help with other things like transportation/employment
- Mead program
- Employment program/supplemental services

11. What tools would you like to be made available to you to provide you with information about any new Medicaid long-term-care health insurance program?

- Options about what level of control they want Team Leader to have
- Internet

12. If you were in charge of any change in the way New Hampshire's long term care service delivery system works what would *you* do? Would it

look anything like the model we are proposing? What makes sense? What doesn't?

- More focus on IDI
- Non medical needs could be provided

Consumer Questions:

1. Is there any other state that has implemented this kind of plan?
2. Does NH employ something already like this under the development disability act?
3. How will the different agencies align?
4. How are we going to pay for this approach?
5. Will dental services be considered a want or an area that the % carried forward could go to

Focus Group

Target Population: Parents of children with developmental disabilities

White Mountain Mental Health, Littleton, NH

September 5, 2013

Conducted by Louis Karno & Company Communications

of participants: 10

Questions

- 1. Have you ever, or do you currently have a care plan?** If so, how was your plan developed? What was your role in developing it? Did anyone help you develop it? Do you feel you were the one who called the shots in developing your plan or do you feel like someone else made most of the decisions?
 - Case manager
 - In home support went over options, rules and guidelines
- 2. How do you feel about your current plan?**
 - Love the agencies that exist
 - Case managers work on an individual basis
 - We have the personal relationship with our agencies
 - Area agencies are very person and family centered
- 3. What doesn't work well with your current plan?**
 - Access problem
 - Travel waste of money because of how far the commute is it doesn't work with an individual who can't sit in the care for a long period of time
 - Its scary that somewhere so far away is making the choices
 - Amount of services and expertise isn't available
 - Very basic
 - Early support system- an area agency is telling parent what she needs even though they don't know,
 - Negotiating with case working
 - Schools have no concept of expertise
 - System is not user-friendly
 - Dealing with Medicare is a nightmare
 - Agencies and doctors don't align
 - Not have the 3-18 not be so dependent on the school system, have more confidence in what northern humane services
- 4. What kind of support would you want or need in not only creating, but implementing your Health Spending Plan?** Would you rather have someone take the lead in developing your plan? or make your own decisions through options counseling?

- The team leader needs to have financial knowledge,
 - Needs to make the financial decision
 - Should be the individual, family member
 - Someone with equal footing
 - Having someone design the plan that actually lives in the area and is familiar with the area
- 5. What incentives would you like available in your plan to help improve your health or help you lead a healthier life?**
- Tuition reimbursement
 - Travel reimbursement
- 6. Would you want to be your own team leader?**
 Yes 10%
 No 90%
- 7. Is there anything in your current plan, or services that you receive, that you are not willing to give up?**
- With the current team- everyone has an equal part on the team
 - Expectation is for everyone to be reasonable and everyone is
 - Team meeting-talk about goals for quarter
 - If he needed something team would discuss it and he would get it
 - Its huge for the family to choose the provider
 - Adaptive programs
 - Respite care
 - Hope not to remove the cyclos because we need the expertise in certain departments
 - Quarterly meetings
 - Family support coordinator – Shannon NC region
- 8. What services would you like to have available to you that you don't have now? What services that you receive now would you like to see more of?**
- Access to specialist ie. Speech, OT, PT, ABA
- 9. What would you use the flexibility in your Health Services Plan for?**
- Adaptive programs
 - Supportive employment
- 10. Are there any obstacles you face in the current system that you don't like and that should be eliminated/addressed in this potential new one?**
- More alignment between the system and the schools, In order to get what they need out of school they will miss what the school has to offer

- Balance in the schools between the system and the programs
- Battle with the services
- Parents need to be educated on laws
- There aren't a lot of jobs out there for people with disabilities, our kids

11. How was your budget developed?

- Hours budget
- Support for kids under 21
- Annual Budget to provide services- pca attendant –choose, adapt sports, respite, management
- Case manager/ in home support went over options, knew rules, went over guidelines

12. How do you find out about information?

- Ourselves
- We do all the leg work
- No one has heard of service link

13. If you were in charge of any change in the way New Hampshire's long-term care service delivery system works what would you do? Would it look anything like the model we are proposing? What makes sense? What doesn't?

- This plan looks a lot like the current school model
- Need to make sure anyone involved with the child is honest
- The healthy actions is penalizing people who can't do the "extra things"
- Budget should be needs based not diagnosis based
- Plan looks good it's the implementation
- Expand upon what the DD already has to include other populations like physical disability, non senior citizens
- Having someone design the plan that actually lives in the area and is familiar with the area
- Life services plan
- Parents are basically the case manager of the kids, we are saving the state so much money Its all about local knowledge and expertise, why are we shipping it out
- One size does not fit all, each region is different
- Afraid for respite in the new system
- Team leader can't be outsourced
- What I have now is not broken and is working well
- Like the concept, question the implementation
- Focus on what is broken

- Do like things more needs and wants based
- Across the life span
- Why do we still have a waiting list
- We haven't been given a chance to give our feedback, how is this plan going to be up and running in such a short time, why was mental health thrown in last minute, did they just want more people to be included. Was it to cut corners?
- Area agencies should be included cause its better service
- Are agency budgets being sliced?

Questions for DHHS:

- Are the types of services specific to "chronic health" ?
- For children services, how does the school Medicaid come into play
- Mental is in step 1 so why is it in step 2?
- Commissioner ignored all the things we've ever said
- We have a current model, why would we change the model we already have? Why not further that? Rather than begin something new, right now we are highly rated in the country
- Will the " team leader" have expertise?
- Is this a medical model, based on a diagnosis?
- Where is the line of what the plan covers?
- Where is the line on the financial side?
- How is this saving us money or the state?
- Why are we paying someone outside the state who doesn't know?

Concerns:

- "The government, governor made us feels like the scum of the earth for applying for Medicaid"
- Before ray Burton was involved it was like pulling teeth to get coverage
- Access here is a huge problem, if we made it more attractive for people to come to where there live for services

Changes in PowerPoint:

- Take out the word health on slide 10
- Slide 11 take out health in bullet # 3
- Slide 17 maybe health comes out in " health services plan"

Focus Group

Target population: Parents of children with mental illness

Organization: NAMI, Concord NH

September 19, 2013

Conducted by Louis Karno & Company Communications

of participants: 9

Questions

18. Have you ever, or do you currently have a care plan? If so, how was your plan developed? What was your role in developing it? Did anyone help you develop it? Do you feel you were the one who called the shots in developing your plan or do you feel like someone else made most of the decisions?

- Wrap around plan/team
- Care team- meets every 6 weeks
 - School depts.
 - Psychologist
 - Psychiatrist
 - OT/PT
 - Psych therapists
- Service care coordinator
- High functioning wrap around team until they graduate

19. How do you feel about your current plan? What works well? What doesn't work well?

- There aren't enough choices
- Not enough long term care support services
- A program that was available in the winter was excellent but its not available any more, more and more programs are being stopped
- Last 3 years have been horrible fighting the system for what my child needs because his situation changes so often
- Problems with program placement
- Too many case managers
- Waitlist is too long
- Not enough choice in counselors, no connection with the counselor once one is assigned
- The care coordinators come and go too often
- "I" do too much work that I shouldn't have to do

20. What kind of support would you want or need in not only creating, but implementing your Health Spending Plan? Would you rather have someone take the lead in developing your plan? or make your own decisions through options counseling?

- Someone to help guide my child based on their needs
- Someone who is periodically following through with the child

- A wrap around team/plan- everyone is associated with the person, funding dictates life plan

21. What incentives would you like available in your plan to help improve your health or help you lead a healthier life?

- Nutritionist
- Wellness program
 - Nutritionist
 - Sports club
 - Social component
- Volunteering
- Incentive with flex funding i.e. alternative therapy
- Credit for staying out of hospital
 - Gift cards

22. Is there anything in your current plan, or services that you receive, that you are not willing to give up?

- Relationships that are already built with doctors and psychiatrists

23. What services would you like to have available to you that you don't have now? What services that you receive now would you like to see more of?

- Housing assistance
- Private counselor/ psychiatrist
- Group home options
- Retirement center/apartment-like
- Assistant living options across the lifespan
- Nutritionist

24. What would you use the flexibility in your Health Services Plan for?

- Wants
- Name brand prescriptions
- Alternative therapy –ie. Art therapy, Music therapy

25. Are there any obstacles you face in the current system that you don't like and that should be eliminated in this potential new one?

- Disconnect between mental illness and developmental disability eligibility
- Eligibility age
- Disconnect/transition issue between graduating high school and “real world”
- DD system doesn't kick in till 21 but Mental Health system services kick in at 18
- School system isn't supportive of kids who appear to be “normal”, don't see any developmental disabilities
- Kids signing themselves out of services once they turned 18

- Guardianship issues
- The ER's procedure in some hospitals prevent parent from being able to leave if child is under 18
- Medicaid took Children's Hospital co pays away
- Not qualifying for services based on geographic constraints

26. What (how much) do you think a fair, annual long-term care health spending plan budget would be for you?

- Depends on individual
- Allowance should be made if additional services are anticipated on being needed

27. What do you think should happen if you need to overspend your annual budget? What do you think should happen if you underspend your annual budget?

- It should roll over to next year
- No money should go back to insurance
- Individual pool and a general pool

28. What would you use any surplus of money for?

- Wants
- Crisis management

29. How do you want to participate in the evaluation of this new long-term-care service model? How do you want to participate in the evaluation of the insurance company who works with you? How about the individual or organization that helps you develop your plan?

- Want to see billing
 - Breakdown of costs for services
- Evaluate services based on price

30. What tools would you like to be made available to you to provide you with information about any new Medicaid long-term-care health insurance program?

- Website with information

31. What would you like to know about the health care providers you "shop" for? How would you like this information to be made available to you? (How do you get this type of information now?)

- Hospitals/doctors covered
- Names and numbers of those covered

32. If you were in charge of any change in the way New Hampshire's long term care service delivery system works what would *you* do? Would it

look anything like the model we are proposing? What makes sense? What doesn't?

- There should be services for a person with a mental disability to transition out of their parents home
- Change to the guardian laws for parents of children with mental disabilities
- Judge granting guardianship to parents of a child with mental disability who is high functioning
- Judge and lawyers who represent "these" kids need some kind of training
- Crisis plan/mobile should be incorporated into the care plan
 - Hospitals covered
 - Who do you go to for information?- names and number
 - Needs to be updated often
- Flex-funding

General questions/concern from participants:

1. Does the life plan follow through for life?
2. Where is the money coming from in this new plan, if the services aren't there to begin with?
3. There should be some kind of incentive for keeping a private insurance.
4. Why would you want to price shop if someone else gets the money from the pool in the end?

Focus Group**Target Population: Seniors****State Council on Aging (SCOA)****October 7, 2013****Conducted by Louis Karno & Company Communications****# of participants: 11****Eligibility/Assessment**

Concern – Alzheimer's or dementia should be included as a condition that qualifies someone for LTC services

Functional ability not solely diagnosis should be should be considered when making an eligibility determination.

For elderly, crisis management is not proactive management. How will they be identified early on?

BIP proposal – no wrong door- incorporates a level one and level two screening

Life plan

If this is prevention and transitions oriented, could care giver support be assessed early on? Could then come up with solutions to issues that may or may not be part of the system, but represent a fulfillment of a persons needs wants and values. If you leave caregiver support issues to far down the line, I worry that all the answers will have to be delivered by formal system responses. And the formal system doesn't response well to "Sally wants to go to the hairdresser."

Families do 85-90% of the caregiving now. Systems and professionals don't want to assume that they have all the answers. They have a hard time responding to "informal" but very important needs. Don't want to undermine the informal system.

Care Team

Is this like an ACT team?

Will these new teams be duplicitous? Will they duplicate what is already in place?

There has been too much competitions between vendors to provide services. It would be better if things were pulled together in an accountable way so we actually know what is going on. Lots of people are vying for a vanishing pot of money. Needs to be more comprehensive.

There are lots of providers who perform home health services, day support services, personal care and even housing support services.

In the non-profit world we have a much different approach to money than for-profit company.

There are lots of people who need services, but they are not necessarily being served.

Some vendors don't deliver the services that are promised – not in the community, done in house

Every time you take money out of the pool to pay for administration there is less for the individual. Can we grow what have or do we re-invent the wheel? We shouldn't do both.

CFI doesn't really address the mentally ill. We currently run programs in silos. You are asking a lot of a team coordinator to navigate the many systems.

One of the problems we have in pulling together ACT teams is that the people you most want on the team are still siloes. The physician doesn't really talk to anyone else. His therapist doesn't really talk to anyone else. And the head of the SAU doesn't really talk to anyone else. So when we have a meeting it's the low level paraprofessionals that show up. Doctors and psychiatrists do their own little thing. The people who really should have an overall picture, really don't get it. They don't want to come. It would cost them money at that level. How do we pull them in?

Payment reform theoretically would create incentives and disincentives to address what you are talking about.

How will this coordinate with the medical home? Accountable care organizations?

Will the team coordinator hold the purse strings for the person's budget? If the coordinator has to coordinate the services, he should control the budget.

Feedback on model

Everyone in DD system has a plan and a budget. Not true in elderly and adult system. The development of an individual budget will be different for providers.

Now you choose providers -- and often the number of choices are very limited.

If providers who provide adult in-home care, for example, could be paid a little extra to deal with people who have mental health issues then the person who goes to the home might have a little training in that area and might feel more comfortable in dealing with those who are harder to serve.

Not all clients are created equal. There should be some allowance made to serve people who are more difficult to serve. If the budget is tied to the person it might help to address this.

There should be some independent control over quality so an agency can't assess a home as a troubled home to get more money.

Team coordinator may need to come in the home to learn what is going on. Will need very good training. If team coordinator represents an agency that provides services – potential conflict of interest – but there could be advantages too.

Team coordinator must be able to think outside the box in order to creatively meet people's needs in a community that have few services.

Guardian model. Guardian is separate from all the organizations. Pulls the services that are needed.

Is this a plan to improve the present plan or a plan that was proposed?

Everything is in siloes right now. This seems to be an attempt to fix that.

Direct Support Professional Focus Group
DD Council, Concord
October 29, 2013
7 Participants

Comment: Does not want MEAD program eligibility to be affected by working. Would like more control of his budget.

Question: If something changes like needs wants or values throughout the course of someone's life, how does the life plan change? Would it be flexible?

Comments:

There is an assumption in this model that organizations will have to exist or be created to do these things and deliver these services

A lot of organizations are flat lining because they have been in existence for so long. There's a need for new. I don't see that happening. Don't assume that the current providers are strong enough to support and deliver on this model.

This appears to require speed and flexibility and I don't see that in the area agencies.

This model seems to be very similar to what we do now. It is not shockingly different to me.

The energy that was there to start the area agencies has faded over the last 10-20 years. From the very days of deinstitutionalization, we have never educated the people who are doing the work. The direct support staff have never gotten the education they have needed and it affects the whole system from the boss on. This has been a huge missing piece. This new system should address this lack of education and training. We've seen the benefits of direct support staff being given just the basic understanding of how to do person center planning you see significant outcomes with people.

What we are saying is that this model doesn't work. You are just telling us what we do every day. It fails because staff do not get the training. Unless you do some new reform -- everyone across the board is going to get better training -- it won't improve.

The people who go out and support these people every day don't get paid well, they don't get training -- they are often just told to "read the care plan" and go out and meet this person and care for them all day. That's our training. Those are the people who are delivering the services. If that's not changed it won't work.

Communication among the "team" is not good. Many case managers have impossible case loads and drop the ball on attending meetings. DSPs are not encouraged to attend the ISP meetings. Sometimes people are given goals by case managers who don't even know

the individual. Often the goal is geared to whatever you are already providing the service for.

But then the problem is, if provider X is not doing a very good job for Bob, we could pull Bob out of that agency, but where else are you going to put Bob? Other agencies are filled to the brim. There's not many options.

We can not hold onto staff. Turnover is a problem. If you are going to send people out there blindly, they don't know what they are getting into and are not going to stick around.

DSPs should be part of life plan meeting. As long as everyone signs their name that they agree to the ISP (program manager, case manager, individual and guardian) there it is. If you sign your name it is assumed that everyone agrees. The individual often says the next day, "I hate this, why did I sign my name to this?" The individual often feels intimidated.

What's the problem? There's a larger issue in the first place. The devaluation of people with disabilities. And people who are closest to the people with disabilities are often devalued as well – often including families.

The most important thing for a person is a provider who is trained, competent and well paid. That's what leads to quality of service and quality of life for this person. Where are they on this chart?

We do this stuff, but often do it half-baked. We put a process in place that takes over the person's needs and desires. We put a plan in place, but that plan often takes over the momentum of the whole situation.

Need to add the well trained provider to the model.

Consumers are often not listened to. That person is not a person anymore.

Comment: I think they (DHHS/workgroups) are looking for someone like small groups like ours to rubber stamp what they are doing. I could show this 30 years ago and it would be the same. It will never happen because it is too hard and people don't want to let go of what they know. On one hand people complain; on the other they don't want it to go away.

The people in the ivory towers know the language and know what people want to hear.

We work with a lot of people who don't have family. It feels very system centered and not person centered.

The individual and the person who works with them every day should be at the center of the team.

People who come from the medical model believe in a very structured daily schedule. I want to do what I want to do when I want to do it. I took a gamble when I hired who I wanted. 30 years ago when I hired someone it took 5 pages of paperwork. Now it's 50. For a \$9.75/ hr. position.

Identifying the right person to represent someone in options counseling is often difficult when they have no one in their life.

When a budget is created, direct support is often the major part of that budget. If you are trying to contain costs we are looking to squish our salaries. Or manage the time they have with someone because we cost something. Society doesn't recognize the value in someone with disabilities or elders because they are consumers versus producers. So that leads to deviancy image juxtaposition. The person in society isn't seen as valuable and the person who works with them isn't either.

The role of the DSP in eldercare, home care, para-professionals for children tends to be custodial. But the dream was to move people out of service land into the community. It becomes self-serving because people are caught in this. We need a more visionary aspect to this. What are we trying to do for people.

Medicaid looks at helping people get food, shelter and clothing. We need to help people stay at home, get jobs, make friends have dates. Most of our peoples' relationships circles are with staff and family. No one measures relationships.

We need to weed out the bad support people and hold people to a higher standard.

Let's go on a different path. How do we keep good DSPs? The office staff gets good benefits. The DSPs don't have anything. Single moms making \$10/hour with no benefits? They can't live on that.

We are working for the system that exists. That's crazy. The poor working for the poor.

There are a lot of lines drawn between roles/jobs in agencies. DSPs are at the bottom. Even managers aren't trained.

I'm a service coordinator I have 28? It ranges between people in apartments and people who are in day programs. You are just putting out fires.

We have people who have 35, even 70.

Evaluating the quality of services usually comes down to, "How is your paperwork?"

You can write anything you want on that piece of paper.

People's lives are being wasted.

But if you nuke that agency for wasting peoples lives, where are those 40 people going to go?

Neither the state or federal govt. goes and talks to the people who get services. If they did, the evaluation of quality would be different.

Focus Group

Target Population: InShape program participants (behavioral health)

Concord Family YMCA, Concord, NH

November 5, 2013

Conducted by Louis Karno & Company Communications

of participants: 5

Most group participants are served by both Medicaid and Medicare. Participants generally did not know which program pays for individual services they receive.

Life Plan/Team

The model as presented (treatment team, treatment plan) with the exception of the budget is similar to what people experience through their involvement with Riverbend Community Mental Health now.

Case managers, therapists, nurses, doctors who prescribe are all part of the team. The case manager is the voice to the client and often the clients voice to the team. There's a yearly treatment planning process and monthly updates as needed.

Budget

Concerns:

- Will having a budget cause limitations to the services people are getting?
- Will we have to make choices between having a case manager and getting medicine?

(People in general have never been told no as to services they might want)

Prevention: currently people who are pre-diabetic can't get nutrition education – it's no longer covered.

For the most part, services the people in group need are available in the Concord area. Geography is not a factor in service availability.

Wellness incentives

This is really complicated. How many people are going to be able to figure this out? Is there going to be someone who can help you walk through this? Your case manager?

Will you have to put your own money in this account?

Does this have anything to do with the new HMO?

Q: Who would you want to help you manage your budget? A: Case manager.

Q: What makes a good case manager? A: They would know this and be able to help you do it.

Q: What makes a good case manager? A: They know you.

Turnover among a person's case managers or therapists can be difficult. They burn out. And then you have to start over with a new one.

The expectations of the job do not always align with the compensation for the job. People feel like they are grinding and grinding and grinding and the bar keeps getting raised.

People who also need to receive the proper training for the job they are doing.

Peer support programs are an important component of a treatment plan and should be part of the services. Sometimes, not always, a peer can be more effective helping in another peer because they have been through the same mental health challenges. As a friend.

Life plan input

It can take a long time to develop a working relationship with a case manager in order to develop a plan.

People in general seemed satisfied with the services they receive and the people they work with.

Treatment plans often have broad and vague goals which are hard to measure. It's hard to tell if people have ever achieved those goals. Life plans should have targeted, measurable goals which have an action plan associated with them.

People need to be helped to help themselves.

Incentives

Q: Should there be consequences if people don't keep their part of the bargain? A: No much support for this

Being good consumers

Q: If you had choices in your treatment plan would you do anything differently? A: I'd skip therapy.

Q: What might you use the therapy savings for? A: More holistic treatment. Maybe try acupuncture.

Working out in the InShape program is like therapy. I get a lot out of it. Maybe more than sitting down with someone. Many group members said they'd choose InShape over talk therapy if they had the choice.

One person gets an explanation of benefits through Cigna (prescriptions?) and CMS? And checks them.

I'd like to know what things cost so I can make informed decisions.

Q: Would you rather stick with what you have now or switch to another system? A: Mixed reaction.

I'd like to see how much things cost, it might be eye opening. But it might be uncomfortable – you hear about how much people depend on the government.

It might be more complicated, but to get more personalized help might be worth it.

Concern: What if I have to go in the hospital with appendicitis? Will my budget be used up?

Prevention

Building peer support can keep people out of the hospital. But it's tough to measure.

Step-Up (a program) keeps you out of the hospital.

Having a whole team of people helping you keeps you out of the hospital.

Summary

Except for the budget piece, the model is very similar to what RiverBend uses. People seem to like the current system. Will need someone to help navigate the new system. Would like to know what things cost. The training and compensation of people who work in the system is import to help avoid burnout and having to start over and over with people.

Q: How important is it to have a RiverBend to help you? A: It's 10 times better. You don't fall through the cracks. From every angle you are getting helped.

Peer Support might be much be cheaper that other support programs.

Focus Group

Target population: People with Behavioral Health Needs

Organization: Peer Support Program, ALC, Conway

November 8, 2013

Conducted by Louis Karno & Company Communications

Attendees: 10

What makes a good case manager?

- She works for me.
- She mediates/interprets between me and whoever I have to deal with. Puts things in layman's terms for me – social security, IRS, employers.
- Turnover can be an issue. It's a tough job.
- Sometimes case managers and therapists overbook and make you wait.
- Sometimes they do things that are not in your best interest like signing you up for a group home that you wouldn't want to live in.
- A good case manager can connect you from one agency to the other.
- They keep you from dropping through a crack
- The process to qualify for a case manager can be bureaucratic.

Self-advocacy is important.

My accident was in 1977 and I didn't get any help til the mid-90s. The system today is much better. Night and day.

Life plans

- Having a direction is essential.
- Setting goals is important.
- We have C-3 teams: psychiatrist, therapist, case manger, a couple of friends

Experience with care teams

- Sometimes these meetings can be uncomfortable. They try to put words in your mouth or try to have you set goals that they think you should set.
- You see things differently than what they are saying and you have a room full of professionals that are telling you what you need to do.
- It helps when you bring someone who is on your side and it helps when you have a really good case manager who is on your side.
- I don't see the need to have these meetings. You see all these people once a week. Why don't the compare notes. What do they have computers for?
- If you disagree with their goals then you are non-compliant.

I believe in self-advocacy. What I allowed the system to do to run me was appalling. Who to go see for doctors, when/how often to see your doctors, what meds to take, "are you taking your meds?" I was too medicated to drive. The turning point was ECT treatments that didn't work.

Options planning and life plan

- That would be good.

Individualized budget

- That would be good.
- What happens if you go over budget? Do you owe out-of-pocket?
- What happens if you meet most of the goals in your plan? Are they going to have and panel to run the budget of will the case worker do it?
- Would there be a choice in how to spend your money?
- Suggestion to keep from overdrawing your budget account: Have a debit card or pre-paid master or visa card. Can help you avoid overspending.

What would you want to know about providers to make a good choice?

- Credentials
- How long they have been in practice
- Location
- It would be nice if there were a list that you could pick from
- On time appointment rate (no overbooking)
- Do they smoke? (don't want someone who takes smoke breaks)
- Is psychiatrist available 24/7 for emergencies
- If there a crisis number available so you don't have to call the hospital and talk to someone you don't know?
- Do they prescribe medication or not?

You need to “click” with a therapist or psychiatrist.

Focus Group**Target population: People with Behavioral Health Needs****Organization: Genesis Behavioral Health, Laconia****December 2, 2013****Conducted by Louis Karno & Company Communications****Attendees: 4****Experience with care teams**

- ACT team has been a very positive experience
- The benefit of a team is having always having someone accountable to pull things together so they don't fall through the cracks.

Life plan

- In the mental health system, people fluctuate. They have times when they are better than others.
- It's hard to move within sections of the system when the person is in flux.
- The system should be fluid. Sometimes you need more care. Sometimes less.
- Housing is important. It has to be part of system innovation. If you don't have housing you won't recover.
- It is hard for someone to help if they have not experienced mental illness or have a family member who has.

When you talk about the life plan I think of the term "purposeful living." You can get trapped where there is no means to an end. Purposeful living gives you back hope, which is a huge void for people.

Mental illness has a stigma**What makes a good team coordinator?**

- I like them to be positive.
- We undervalue the role of care or case management. Turnover. Low pay.
- Having a team approach is great, but it needs to be fluid. There are so many acute care episodes in mental illness. Patients improve for a few months or at most a year before they have that fluid pocket happen again.

Long term care has to be fluid – incorporate acute care.

Acute care seems to have precedence over long term care. The mental health system is inadequate.

The long-term-care system has to include more service options.

Would this system allow the flexibility to have a team when you need it, stop when you don't, and get back in when you do? It needs to be fluid.

Individualized budget

- I would not be ready for this. It would not work for me now.

Service options

- Homeopathic or acupuncture or other holistic care might help.
- Yoga

Shopping for services

- Now, therapists are assigned.
- What happens if everyone wants the same therapist?
- Turnover in therapists is problematic. You have to start all over again.
- I would want to know background and treatment philosophy.
- I don't know if anyone can say what is going to work. Trial and error is important. Knowing you can have the ability to change on your own versus being told that you can is the tough piece. We as consumers want to be able to choose. It's about finding the right fit.

Budget

- Does someone have to be in a certain financial pocket?
- What happens if something unexpected comes up?

The DD System gets priority over the Mental Health System. We don't have the ability to pay for what they get. I know it's underfunded and they are fighting the good fight, but I'd love to get what they get.

Need choice. System has to be fluid enough to meets the needs at the time.

Need community breadth of services – housing, crisis, respite.

Advocate

- You don't know what you need. You don't know what to ask for. You need help. Don't ask, "What can I do for you?" You need an advocate.

Focus Group**Target population: People representing the elderly****Organization: ServcieLink, Keene****December 4, 2013****Conducted by Louis Karno & Company Communications****Attendees: 6****On Medicaid eligibility**

- One side of the coin tells you one thing – one side tells you the other.
- The financial eligibility process is way too complicated and burdensome.
- To have to wait 45 days when you have less than \$2,500 is unreasonable. There has to be a happy medium between fraud prevention and helping people.
- Reduce the look-back period to a more reasonable time frame – maybe 3 years instead of 5.
- There are many people who don't have family or people to help them with the paperwork. What are they supposed to do?
- It's cumbersome. The stack of paper I had to bring in was ridiculous – and where you have to go to get it . . .
- It's good that they don't count the spouse's income. It wouldn't help to make me broke.

Life plan

- Good idea.
- The Life Plan should be done 5 years out -- before you apply for Medicaid (for people with dementia).
- The earlier the better. We are an aging society. Dementia and Alzheimer's are becoming epidemic. So you are dealing with people with memory issues. The earlier you try to create a plan the better. And if you can do something with the whole family, and not just the actual person who needs the care, that's better.
- Family might not be actual family, they could be the people who know that person the best.
- You need someone to help guide you through the system before you need the system.
- I had no idea what help I needed for my wife. You need someone who can help you figure out what you need and steer you to all these different places that are out there. You don't know what to ask for because you don't know that they are there.

The system makes it twice as hard to keep a family member at home than to put them in a nursing home.

These 2 gentlemen need help now, not in 45 days.

People can't wait 5 years to get in a nursing home. It's financially impossible.

Budget

- I have dealt with Granite State Independent Living and ServiceLink and they are very helpful.
- Budget is appealing. You could pick and choose. There are some things my mom can do on her own, but there are some things she could use help with 2 or 3 times per week.

How should ServiceLink or the early life planning or other services be promoted?

- Advertising
- Promote through doctors' offices
- Gerontologists
- It would be great to have a pamphlet or book with all the services available.
- You only keep in your mind what you need to know right now. So need to give the same flyer or pamphlet to people every year until they need it.

Medical evaluation

- Why can't you retroactively pay back the home care a person needs until they are eligible – like they do at a nursing home?
- Nurses may not show up for an in-home medical evaluation for 45-days to 2 months, but they'll do it in a day at a nursing home. Need to get more nurses out quickly.

Services

Need transitional housing

Advocate

Someone with memory needs may not be able to communicate what they need. They need an advocate.